

End of life care

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

A disability is no reason to withhold medical treatment to a person, including treatment needed to keep the person alive. Sometimes, medical treatment is not offered to people with intellectual disability because of doctors' views about their quality of life. Family and support workers may need to be educators and strong advocates in these situations.

However, death comes to all people and it is wise to prepare for it. This includes thinking about what treatment will be in a person's interests when they have a health condition that may limit their lifespan. It also includes how to make the end of a person's life as positive an experience as it can be.

We all die sometime

As people age, the end of life becomes closer. Also, some people have health conditions that may shorten their lives, for example chronic lung disease. In either case, it is sensible to start thinking about how the person wants to live the rest of their life and about issues that may arise when they are dying. This can be done through discussion between the person with intellectual disability, family, any other advocate, disability support workers and health professionals. Sometimes, an individual plan meeting is a good time to do this. These issues need to be discussed in a way that is very sensitive to people's fears and emotions but also allows people to express their views freely.

A person's culture may affect who should be involved in discussions and how they should proceed. For example, in Aboriginal communities, it is common for the extended family and community to participate in decision making.

Discussion of end of life issues becomes very important when a person has a terminal illness - an illness that will lead to the person's death. There should be a meeting with a palliative care service. GPs and hospitals can link patients to palliative care services.

The person with intellectual disability should be supported to have maximum involvement in all these processes. The person's views and values should be at the core. If the person understands the nature and effect of decisions, their decisions should be respected. Plans should be worked out by discussions involving the person, family and other relevant people - the discussions should aim for a consensus about what plans are in the person's best interests.

The **Talking End of Life** with people with intellectual disability (TEL) toolkit gives family members and professionals the skills and resources to help people with intellectual disability understand and make plans for the end of life.

Issues to think about

The issues to think about will vary with the individual and the situation. Some common questions are:

- Would I be surprised if the person died in the next 12 months? This may help to decide whether a discussion about end of life should be initiated.
- How can the person's quality of life be maximised as their life comes towards an end? For example, it is usually good for the person to stay in their home for as long as possible - are home modifications, extra equipment and extra support needed? What support will help the person to keep doing their usual activities? If the person has trouble eating and drinking normally, how can their diet be modified?
- Are there particular hospitals and treatments that the person does or does not like?
- How can pain be managed?
- Would some treatments be of little benefit and possibly add to the person's suffering?
- If the person has a terminal condition, should they be resuscitated if their heart stops beating? A hospital will sometimes suggest placing a "not for resuscitation" ("No-CPR" or "DNR") endorsement on a person's file. This issue needs to be approached very carefully. If a "not for resuscitation" endorsement is made, there should be very regular reviews of both the person's condition and the endorsement. All other treatments that will benefit the person should still be provided.
- If the person has a terminal condition and reaches the point where they cannot eat or drink normally, should they be tube fed?
- Does the person have religious, spiritual or cultural needs to be met when dying?
- What sort of funeral would the person want?
- Does the person have a will? If the person wants to make a will, it will be important for a lawyer to see the person and prepare it. The lawyer will need to carefully check that the person has the understanding needed to make a will.

- What support do family, close friends, co-residents and support workers need to deal with a person's terminal illness and death?

The interests of the person with intellectual disability must be paramount in considering these issues.

All end of life plans should be regularly reviewed. The person's condition may change, treatment advances can occur and people can change their minds.

Ways to put plans in writing

Sometimes, future care planning can be included in a person's individual plan.

In other cases, a more specific plan may be better. The names given to these plans vary with the circumstances in which they are prepared. **An advance care plan** spells out how to deal with situations that are likely to arise at the end of a person's life. It can spell out a person's wishes about things like what treatment they want or do not want. Advance care planning often occurs when a person has an illness that may shorten their life.

A **palliative care plan** focuses on the coordinated care which will be provided for a person who is terminally ill. It can include pain relief, diet advice, physiotherapy and how to keep the person active. It can also cover grief and bereavement support for the person and others close to them.

All these plans are guiding documents. They are not legally binding. Consent is still needed when a particular treatment arises and consultation is still needed if a doctor is considering withholding treatment.

Sometimes, people also make legally binding **Advance Care Directives**. These spell out treatment that the person does not want in particular circumstances, for example some people sign directives saying that, if they are terminally ill, they do not want to be resuscitated or tube fed. These directives come into play if the person becomes unable to make decisions, for example due to being in a coma. Doctors must follow Advance Care Directives if they clearly cover the situation that arises and if the person understood the directive when they made it.

If a person with intellectual disability wants to make a directive, they should be provided with support to understand the decision they are making and a person like a clinical psychologist should assess their understanding.

No one else can make an Advance Care Directive on behalf of a person with intellectual disability.

Another option is to make an **appointment of enduring guardian** - a person appoints their own guardian to make decisions about things like medical treatment if they lose capacity to make their own decisions. An intellectual disability may prevent a person from having the understanding to make an appointment of enduring guardian. The person's understanding should be assessed and they would need legal advice.

The law and end of life decisions

If an adult understands their condition and proposed treatment, it is up to them to decide whether to have the treatment. Wherever possible, a person with intellectual disability should be supported to make their own decisions.

For adults who cannot understand their condition and the proposed treatment, their views should still be taken into account. NSW law says:

- Providing treatment requires consent from a “person responsible” (usually a close family member or guardian) or the Guardianship Division of the NSW Civil and Administrative Tribunal.
- In an emergency, the doctor can treat without consent.
- Decisions about withholding or withdrawing life sustaining treatment for someone who is dying are generally made by consensus. This includes “no CPR” decisions. However, if there is a guardian with authority to make health care decisions, they decide. The law does not assume that a person’s best interests are always served by extending life.
- If there is a dispute about what should occur, you can consider applying to the Guardianship Division for consent to treatment or appointment of a guardian. Only the Supreme Court can force a doctor to treat. Usually, people should try to talk through a dispute before going to the Guardianship Division or Supreme Court.

For children with intellectual disability, similar rules apply as for adults with guardians. Parents usually decide about treatment issues.

Resolving disputes

The approach described in this fact sheet is along the lines of what NSW Health expects doctors to do.

If possible, it is best to work through disagreements by discussion and negotiation, as long as the final decision is in the interests of the person. The person with intellectual disability will often need time and support to think through information that doctors give them. Sometimes, a second opinion from another doctor may help, especially if that doctor is experienced with people with intellectual disability. You could try to get advice from a specialised intellectual disability health service. You can also consult a disability advocacy group. Sometimes, a skilled facilitator can be brought in to help you and the health professionals talk the situation through.

You can also consider approaching a formal complaints body. See the **Rights and complaints** fact sheet.

A last word

We all would want the end of our life to be as dignified and comfortable as it can be. Good communication between the person involved, family, doctors and others should achieve this aim for people with intellectual disability.

For more information

Talking End of Life ...with people with intellectual disability toolkit

www.caresearch.com.au/caresearch/tabid/4778/Default.aspx

Advance Care Planning

www.health.nsw.gov.au/patients

End of Life Decisions, the Law and Clinical Practice

www.healthlaw.planningaheadtools.com.au

Responding to Needs of People with a Disability during Hospitalisation, NSW Health

www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017_001.pdf

The Guardianship Division of the NSW Civil and Administrative Tribunal has more detailed information on guardianship and medical consent.

Phone (02) 9556 7600 or 100 006 228 National Relay Service 1300 555 727

www.ncat.nsw.gov.au

In other parts of Australia, the law is different to NSW. Contact your local Public Advocate or Guardianship Tribunal. Find the relevant information at the Australian Guardianship and Administration Council

www.agac.org.au

You might be interested in these fact sheets

- Ageing and health
- Consent to medical treatment
- Rights and complaints

This fact sheet was updated in **2018**.

The fact sheet contains general information only and does not take into account individual circumstances. It should not be relied on for medical advice. We encourage you to look at the information in this fact sheet carefully with your health professional to decide whether the information is right for you.